A Grounded Theory Study Of The Bereavement Experience For Adults With Developmental Disabilities FollowingThe Death Of A Parent Or Loved One: Perceptions Of Bereavement Counselors

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Statement of the Research Problem

Research on bereavement for adults with developmental disabilities (DD), especially those with mental retardation, has been very limited (Kauffman, 2005). Studies do exist on the conceptual understanding of death for adults with DD (Kennedy, 2000; Kuekes, 1996; Levelle, 1997; Lipe-Goodson & Goebel, 1983; McEvoy, 1989), but little work has been done on the socio-emotional experience of bereavement for this population. Since "grief does not focus on one's ability to 'understand' but instead on one's ability to 'feel'" (Wolfelt in Nolen-Hoeksema & Larsen, 1999, p. 122), it is irresponsible to ignore how adults with DD experience -- understand and feel -- bereavement after parental death. By continuing to presume that adults with DD grieve like adults without DD (Higgins, 1992), we assume this population views and experiences life without any exceptional differences. This assumption is untenable. Exploring bereavement after parental death or death of a loved one for adults with DD is important because a knowledge base about the nature of the bereavement experience for this population is very limited and the need for informed guidance is so great.

The assumption that adults with DD understand death concept the same as children of the same developmental level has been put in question by Kennedy (2000), Levelle (1997), Lipe-Goodsen and Goebel (1983), and McEvoy (1989). Assumptions regarding lack of ability to attach have been challenged by early efforts to document feelings of grief after loss and bereavement (Bonnell-Pascual et al., 1999; Dell'Aquila, 1996; MacHale & Carey, 2002). Dell'Aquila (1996) and Kauffman (1994) argue that continued adherence to these assumptions, in fact, could cause harm in denying expression of human emotion. In addition, it is irresponsible to apply general bereavement theory to persons with DD. Generalizing findings from studies conducted using adults without DD to those using adults with DD assumes that they grieve the same as the general population, with the same risk factors for atypical grief. Such

generalization assumes adults with DD need the same grief interventions at the same time as the general population. How responsible is this when their lives are often lived out in different spaces and contexts than the general population with less personal control over their decisions and activities? As Dell'Aquila noted, adults with DD do not have avenues to process feelings about relatively minor emotional experiences. Will bereavement losses be more complicated due to accumulations of long ignored feelings? Will bereavement losses have greater impact on their lives? Will health care professionals continue to treat emotional disturbances that could be bereavement reactions with medication and behavior programs and not address the underlying problems? Intentional practice needs a strong theory base. The theory base is currently nonexistent for adults with DD experiencing bereavement.

Research Background and Hypotheses

As individuals with DD face bereavement, the community and their caregivers are ill prepared to assist them (Bennett, 2003). Higgins (1992) notes unsubstantiated assumptions are made that if adults with DD grieve, they go through the same grieving process as the general population. Social networks tend to be sparse, especially if the adult lives with family (Grant, 1993; Krauss & Erickson, 1988). Krauss and Erickson found that "family members played a pivotal and somewhat exclusive role in the lives of their relatives with mental retardation who had not been placed in formal residential settings" (p. 200). Persons with DD often have communication and behavioral differences that make the identification of healthy versus unhealthy grief even more challenging than in persons without a disability. Death of a family member has been documented as a trigger for symptoms of psychopathology and cause for crisis intervention for individuals with DD. (Bonnell-Pascual, et al., 1999; Dodd, Dowling & Hollins, 2005; Emerson, 1977; Kloeppel & Hollins, 1989; MacHale & Carey, 2002). Grant (1993), in his study of support networks and transitions, found that deaths in the family "were talked of as having profound, long-lasting but not always well understood effects on the person with a mental handicap" (p. 47). Kaufman (1994) blames the overall dehumanization of people with DD for historical oversight in acknowledging grief in this population. Van Dyke (2003) states, "In my experience of counseling people with disabilities who lose their only parent, it is not the finality of the loss, but the after effects of poor planning or no planning whatsoever that leave the deepest emotional scars." (p. 38). Gradually, social scientists and providers of care have begun to acknowledge that depth of human feeling exists for those whose cognitive abilities fall below a standard score. Little work has been heretofore completed on adults with developmental disability and the bereavement experience.

Research is beginning to emerge on bereavement for adults with DD. Emerson (1977) wrote of being called in as a consultant for adults with DD who were displaying emotional disturbances. "Crisis intervention approaches routinely try to find a precipitating stress: by looking for one, I have found that 50% of the time there has been either the death or loss of an individual close to the client preceding the symptoms" (p. 46). Read (2000) speaks of the loss history of most adults with LD. Few have even a "written history of their past" (p. 230). Kauffman (1994) argues that adults with DD have been dehumanized by the oversight of their emotions, especially by the lack of

acknowledgement of their reactions to loss and bereavement. Kauffman labeled the grief of persons with DD as disenfranchised.

McDaniel (1989) described a bereavement group of eight males with DD. The participants reported feeling of being left out of family experiences when someone was very ill, and worried over who would look out for them after their parents had died.

Oswin (1991) interviewed individuals with DD and their families. She stated that staff often focuses on the disability. They do not expect to see, therefore miss recognition of signs of grief. She speaks of the secondary losses of home and community that isolate the grieving individual even further. Oswin describes the disempowered position of adults with DD in society and the misguided efforts to protect them from reality. Oswin's findings are best summarized by, "The differences between experiences of loss for people *without* learning difficulties and those *with* learning difficulties was shown not in the reaction of the latter group but in their vulnerability and in other people's attitudes towards them." (p. 142)

Hedger and Smith (1993) reported unique and individualized grief journeys for their research participants. Dell'Aquila (1996) noted that her participants had few opportunities to process the thoughts and feeling around most life experiences and that this was especially true for bereavement experiences. She found "the social experience of being developmentally disabled does create a disadvantaged state from which to approach grief" (p. 108). Bonnell-Pascual et al. (1999) completed a study of bereavement in adults with learning disabilities. The authors noted that from quantitative data gathered "it was hard to disentangle… the effects of the bereavement itself and the effects of associated life changes" (p. 350). From the qualitative data, however, the authors noted an extended period of mourning, as well as the "continuing sense of loss… demonstrated through things such as tearfulness, crying out for the deceased parent, mood swings and physical symptoms" (p. 350).

Read, Papakosta-Harvey and Bower (2000) completed a study focused on bereavement support group outcomes and outcomes of a workshop on loss. Two key themes emerged from interviews: confusion and frustration with understanding the loss and loss causing them to lose control of important life decisions.

It has only been in the recent past that adults with DD have been asked to speak for themselves, providing researchers with limited knowledge about their lived experience. The context of their experience must be explored, including their living situation, their supports, and remaining family, as parental bereavement is often a life altering event for everyone with or without disability (Angell, Dennis, & Dumain, 1998).

Cognitive differences do exist, yet do emotional processes differ? Since the time of Freud, social scientists have struggled to explain and predict the outcome of bereavement for the general population. Clear understanding of the complex process of bereavement has still not been achieved in the empirical world. Adding developmental disability to the mix creates even greater uncertainty as to outcomes.

The need to document the bereavement experiences of adults with DD and compare them to adults without DD is the course researchers need to pursue. This study

explored bereavement counselors' observations of adults with DD who had experienced loss.

My goal was to explore more about bereavement for adults with DD. To gain further insight into these issues, I asked two focused research questions. 1) How do bereavement counselors perceive the experience of bereavement for adults with DD? 2) What do bereavement counselors perceive as being helpful during bereavement for adults with DD?

Methodology

I selected qualitative research using grounded theory methodology to answer the research questions. My first reason was not enough is known about persons with DD and bereavement, and qualitative research provides a base (Devers & Robinson, 2002). The second was that grief that results from bereavement is not an entity that can be objectively measured and explained by quantitative methods (Bryman,1984). It was my premise that the phenomenon of grief is not an entity that can be known and described as a static event; neither can it be measured separately from the researcher and the subjects. The researchers join the participants in this search for the reality of loss that can only be known in the "realm of the knower" (Smith, 1983, p. 46). The complexity of the social worlds of the participants is acknowledged, as Smith noted, and is too complex for laws of causality. Two noted bereavement theorists, Phyllis Silverman and Dennis Klass (1996), discussed the appropriateness of research methods to study grief: "[The empiricist] approach dismisses the subjective experiences of people and minimizes the importance of relationships in the human experience because these are difficult to study in their model." (p. 21)

My own model of grief is important to reveal as Kirk and Reid (2002) state: "How that problematic or undesirable state is understood by the practitioner is usually relevant to the selection of the intervention and its objectives." (p. 71) This is true for researchers as well. It is not just the methodology (for instance, a comparison group study versus structured interviews) that is important. What is key is how I view reality and how I could come to "know" a social and emotional phenomenon termed bereavement. I view bereavement as a complex, multi-layered phenomena. There are behaviors that can be observed and noted, but there is another level of experience that only a person living in that situation can describe and explain. A challenge existed for me to be clear about my own background, but to bracket my own perceptions as I gather and read the data. I have already made the point that bereavement for adults with DD is new territory. Coupling the state of research with my own perspective on reality mandated the use of qualitative study. The proposed study will utilize qualitative research techniques in general, and grounded theory specifically.

Research, whether quantitative or qualitative, is aimed at "discovery and explication of theory" (Devers & Robinson, p. 242). Grounded theory, as developed by Glaser and Strauss (1967/1999), works to derive theory from the data as they are collected from participants. Charmaz (1990) described four phases of implementing grounded theory: creating and refining the research, data, and the collection questions; raising terms of concepts; asking more conceptual questions on a generic level; and

making further discoveries and clarifying concepts through writing and rewriting (p. 1162). The data are examined for concepts, concepts are reviewed looking for repeated themes, and relationships are analyzed between theoretical categories.

I have worked in hospice settings for six years and with people with DD for nineteen years. This background gives me credibility in analyzing this particular data, but added a responsibility in being accountable for interpretation of the data based on my experience and background. As noted by Strauss and Corbin (1998a), this professional knowledge allowed a deeper awareness of issues that are brought out by the participants. On the other hand, how I situated myself with regard to disability had a profound affect on how I *see* and *hear* the data. Although I did not impose these views on the participants or on the data, they affected how I filtered and interpreted what is said, and how I framed and organized the data. I bracketed my own views as much as possible. However, I understood my worldview would impact the interpretation and analysis phase of research. The point at which this interpretation becomes most evident is where the codes that emerged from the data and the deeper meanings were explored. Additionally, the counselors who participated reported the clients' experiences from their own filters and perspectives, which have been influenced by their own life experiences and professional education. I experienced a true interplay with the participants and did note "reciprocal shaping" (Strauss & Corbin,1998b, p. 173). The constant challenge was making sure that the codes and themes really emerged from the data, not from my previous knowledge or other readings. Great care was exerted to take concepts that emerged and then to reaffirm that the data were there to support them.

Interviews continued to add data until no new categories or properties were emerging, or to the point of saturation. Saturation was close after 12 interviews. After 15, it was clear no further categories were going to emerge. Nineteen interviews were completed. A colleague was given three interviews to blind code. She was later given a list of my original codes, merging history and rationale for the conceptual categories and themes to verify my analysis. My chairperson also read the codes and to ascertain agreement with whether or not they truly represented the data.

The raw codes, or surface concepts were analyzed to attain the deeper conceptual categories. In addition, two major themes emerged and will be discussed in the following section.

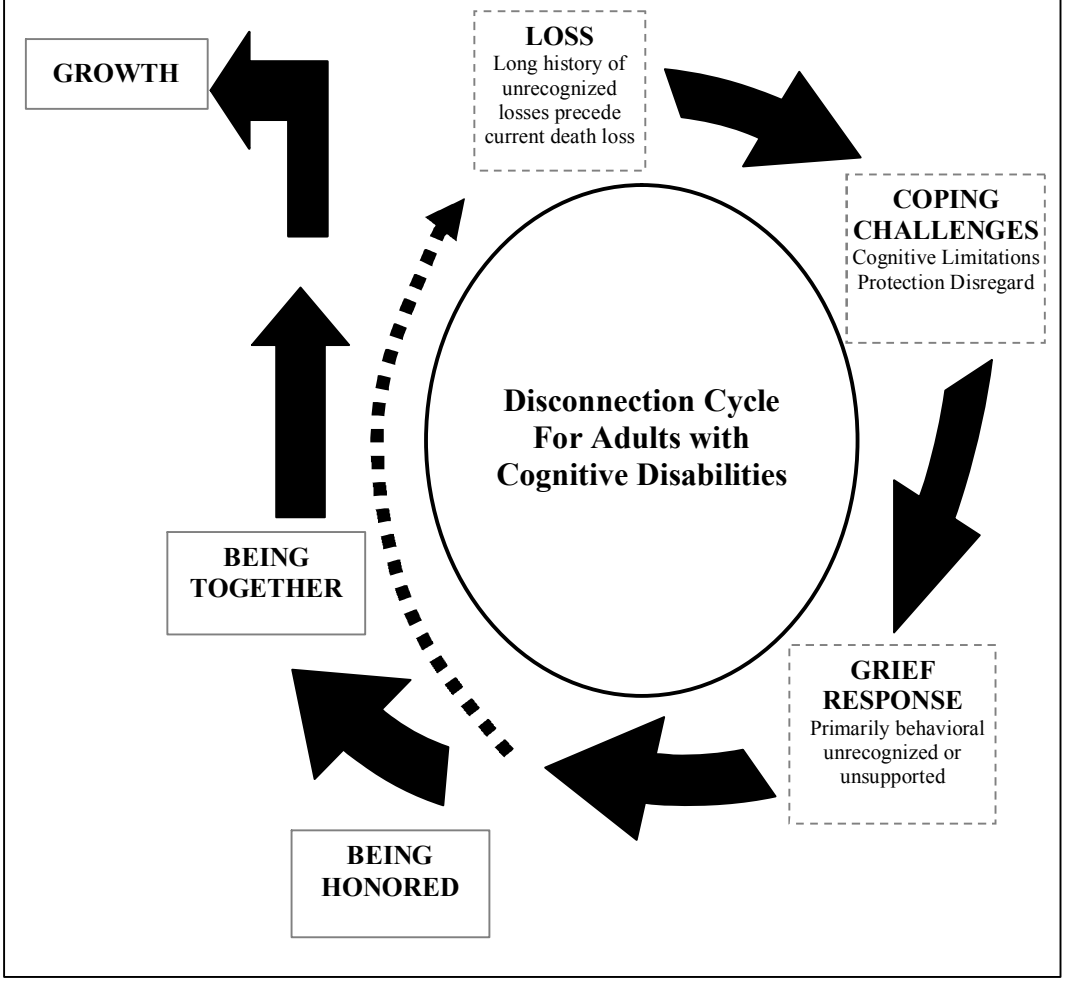
Results

In summary, the data revealed five categories and two major themes. The categories were Loss, Grief Response, Coping Challenges, Being Honored and Being Together. The categories organized themselves into two themes, Disconnection and Growth**.** Loss, Grief Response and Coping Challenges illustrated the broader theme of Disconnection.

Table I. Examples of Data Excerpts Linked to Five Categorical Concepts

LOSS	GRIEF RESPONSE	COPING CHALLENGES	BEING HONORED	BEING TOGETHER
...people forget to think about them.	...wanting to search for them. "When are they coming back?"	...very uncomfortable with very strong feelings	...a structured session as opposed to a non-structured one	A lot of rituals… get a linking object, a memento...
"Your sister called and your father died last week."	She's afraid now that everyone around her is going to die.	They don't have as much control over their lives or as many resources or choices	What we're dealing with for healing is support	...map out things that they might expect to feel
This one particular person was never told.	...the same heartache and feelings that anybody else does	Very black and white thinking… Very, very concrete.	just to find out where I can connect with them	you have to make this connection, that OK, you do this, this, and this.
Not bringing them to say goodbye.	There's so much deep sadness.	I'm not sure I can hear what they're feeling.	...incorporate them and mentor them… Don't negate those feelings.	working with staff...With their world kind of turned upside down by the loss ... structure helps.

Figure 2. **Disconnection Cycle And Potential For Growth**



Even secondhand, the stories of unrecognized losses of opportunity, independence, friendships and loved ones were staggering and formed the category of Loss. The challenges of dealing with loss without information, inclusion or practice with coping skills were starkly evident and led to the category of Coping Challenges. The grief reactions reported were primarily behavioral, intense, yet sometimes mislabeled or overlooked by caregivers. The reactions were grouped into the category of Grief Response. The bereavement counselors' stories of client eagerness for individualized interventions and client gratitude for being heard laid the foundation for the categories of Being Honored. Reported evidence of healing and positive results from counselors' efforts to work with the client to identify feelings and behaviors related to grief, as well as work with staff and families to create safety and stronger support generated the

category named Being Together. Figure I depicts both the cycle of Disconnection and the potential for Growth that can occur with proper education and support for adults with DD their caregivers, and other service providers.

Utility for Social Work Practice

The grounded theory explanation of bereavement that emerged from this study has urgent implications for practice and policy. The cycle of disconnection described by the participating counselors can be used as a powerful depiction of the need for change. The counselors' belief in the potential for growth for adults with DD holds promise that professional and community efforts can help move adults with DD through grief and loss towards hope and healing.

One of the first steps for change is the need to educate others about the depth and breadth of loss for this population, including history of losses, secondary losses, protection, and disregard. Work in these areas requires prevention work, in terms of early death education and early involvement, and notification of any anticipated changes. Caregivers, as well as professionals, would benefit from mentoring in ways to honor individual needs and ways to *be with* clients with DD. Interrupting the continual cycling of loss requires attention to the coping challenges of adults with DD, which include cognitive issues, verbal communication issues, and lack of skills, complicated by caregiver and professional discomfort. Improvement must include teaching caregivers, as well as professionals, how to enhance their own knowledge, understanding, and comfort with loss and grief. This must be coupled with training on varied methods to increase coping skills for adults with DD.

For social workers who find themselves working with adults with DD it is important to honor these individuals as you would any other client by listening to non-verbal as well as verbal communications. Acknowledge their humanity. Depending on the abilities of the individual with DD, be ready to use a variety of methods from very concrete activities such as collage, clay work and music to purely verbal interventions. Specifically, the following guidelines have been suggested by the bereavement counselors in the study. Provide a supportive presence; being with others who listen and acknowledge is key. Help the client redeveloping a secure base-keep structure/safety.

Give the client information that is concrete. Advocate for client inclusion in events/decisions. Help facilitate opportunities for the client to participate in rituals of remembrance. Recognize that the client's lack of their ability to communicate fully does not mean she or he doesn't experience a loss deeply and profoundly.

We must work to educate social workers as well the community. Mentor others or find experienced mentors for one's professional practice, attend seminars and search the literature. Our mission is to improve understanding the myriad of ways grief response can be communicated, so grief can be made visible and its depth and effects honored and witnessed for all.

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